

# **Clinical Gerontologist**



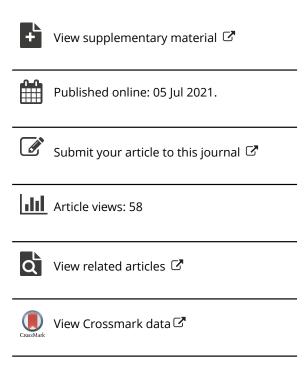
ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/wcli20

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**To cite this article:** Megan E. Gately, Sarah Muccini, Brady A. Eggleston & Jaye E. McLaren (2021): Program Evaluation of My Life, My Story: Virtual Storytelling in the COVID-19 Age, Clinical Gerontologist, DOI: 10.1080/07317115.2021.1931610

To link to this article: <a href="https://doi.org/10.1080/07317115.2021.1931610">https://doi.org/10.1080/07317115.2021.1931610</a>







# Program Evaluation of My Life, My Story: Virtual Storytelling in the COVID-19 Age

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#### **ABSTRACT**

**Objectives:** COVID-19 negatively affected older adults' well-being and quality of life, particularly individuals with dementia. My Life, My Story (MLMS) was developed at Veterans Health Administration as an opportunity for Veterans to interact and share life stories using guided interviews. This paper describes a program evaluation of MLMS delivered to Veterans with cognitive concerns and their caregivers using telehealth technology during COVID-19.

**Methods:** Fourteen Veteran-caregiver dyads completed MLMS interviews with occupational therapy trainees using telehealth technology. Most (10 of 14) participating Veterans had mild-to-moderate dementia. Trainees ascertained Veteran and caregiver demographics such as age and recent cognitive evaluation scores via chart review. Trainees also gathered Veteran-caregiver technology and interview experience through post-interview program evaluation questionnaires. **Results:** Dyads reported generally positive interview and technological experience, despite technological glitches occurring in most (approximately 70%) interviews. Caregivers assisted with videoconferencing setup and participated in ten interviews.

**Conclusions:** Veterans with cognitive concerns successfully participated in virtual MLMS interviews during COVID-19. Caregivers enhanced Veteran engagement and often provided technological support. **Clinical implications:** Telehealth technology enabled participation in My Life, My Story by individuals with cognitive concerns and their caregivers. Post pandemic, clinicians may consider integrating telehealth technology with patients facing access challenges.

#### **KEYWORDS**

Telehealth; life narrative; storytelling; videoconferencing; dementia

# Introduction

In response to COVID-19, many older adults avoided face-to-face social contact and leaving their homes (Le Couteur, Anderson, & Newman, 2020). While this decreased exposure to the virus, doing so may have increased social isolation, anxiety, anger, stress, and agitation, particularly for individuals with dementia (Canevelli, Bruno, & Cesari, 2020; Cheung & Peri, 2020). Dementia is noted for causing declines in function and cognition related to memory and language, often impairing the ability to connect and communicate ("2020 Alzheimer's disease facts and figures," 2020). The forced isolation of COVID-19 resulted in fewer opportunities for engagement, which may have exacerbated dementia symptoms (Numbers & Brodaty, 2021).

Technology offers an alternative to face-to-face dementia care (Astell et al., 2019; Goodman-Casanova, Dura-Perez, Guzman-Parra, Cuesta-

Vargas, Mayoral-Cleries, 2020; Freddolino, Comas-Herrera, Knapp, & Damant, 2019). Telehealth has been utilized for telepsychology services (Chen et al., 2020; Poletti et al., 2020) and dementia assessment and management. Such remote care has been delivered between two clinic locations (Chang, Homer, & Rossi, 2018; Dang, Gomez-Orozco, Van Zuilen, & Levis, 2018; Lum et al., 2020; Pimentel et al., 2019; Powers, Homer, Morone, Edmonds, & Rossi, 2017) and into patients' homes (Lindauer et al., 2017; Malmgren Fänge et al., 2017; Moo, Jafri, & Morin, 2014; Shaw, Williams, Lee, & Coleman, 2021). Telehealth has been utilized for dementia-related caregiver support (Austrom et al., 2015; Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013; Griffiths, Whitney, Kovaleva, & Hepburn, 2016; Lindauer et al., 2018; Williams et al., 2018), rehabilitation (Burton & O'Connell, 2018; Gately,

Trudeau, & Moo, 2019), and home safety (Gately, Trudeau, & Moo, 2020).

My Life, My Story (MLMS), which involves patients' personal narrative interviews, was developed by Veterans Health Administration (VHA) Office of Patient-Centered Care and Cultural Transformation (Nathan et al., 2019; Ringler, Ahearn, Wise, Lee, & Krahn, 2015; Roberts, Ringler, Krahn, & Ahearn, 2020). MLMS aims to increase connectedness between Veterans and patient aligned care teams (PACT) and improve quality of care through patient narratives developed using a guided interview process. MLMS often employs hospital staff, including clinicians and trainees, as interviewers (Nathan et al., 2019). MLMS has been implemented at approximately fifty-five VHA locations across the nation (Ringler et al., 2015), including VA Bedford Healthcare System. This paper describes a program evaluation of My Life, My Story delivered using telehealth to Veterans with cognitive concerns and their caregivers.

#### Methods

Three occupational therapy Master's-level clinical trainees conducted My Life, My Story interviews with Veterans affiliated with VA Bedford Health Care System between July and August of 2020. Prior to interviews, trainees underwent training in MLMS guidelines and principles, including a Veteran-centric approach to facilitate storytelling (Nathan et al., 2019). Eligible Veterans were previously evaluated for cognitive concerns at the outpatient neurocognitive clinic, referred by the clinic social worker, and had access to at least a telephone. There were no other exclusion criteria. Trainees called Veterans to invite them to participate. To ensure dementia-capable care, which recognizes caregivers' collaboration (Borson & Chodosh, 2014; Jennings et al., 2019), trainees also invited caregivers to participate.

Veteran-caregiver dyads could participate using videoconferencing, phone, or a combination. Veterans used VHA's HIPAA-compliant videoconferencing platform, VA Video Connect (VVC), or a commercial platform. Trainees assisted with technological set-up before the scheduled interview, videoconferencing including sending

Interviews were not recorded or transcribed, but clinical trainees took note of interview details to construct the personal narratives, and details such as devices utilized, who set up technology, approximate number and duration of technical issues, and interview length. Trainees and supervisors also participated in regular group discussions about interviews, including perceived challenges, for their clinical training.

Following interviews, trainees wrote Veteran stories in Microsoft Word (using notes), which is how word count was ascertained. Veteran stories were written in first person to reflect Veterans' voice and tone. A story readback was scheduled within a week of the interview in which trainees read completed stories to dyads, who had the opportunity to provide edits. Once approved, finalized stories were entered into Veterans' medical record and hard copies were mailed. In accordance with institutional procedures, this project was reviewed by VA Bedford's Institutional Review Board. The IRB deemed the activity to be not research but an evaluation of an existing hospital program. Though deemed not research, the project was conducted in adherence with VA ethical and privacy protections.

# **Participants**

Forty-one Veteran-caregiver dyads were referred. Twenty Veteran-caregiver dyads declined, for reasons including bad timing or lack of interest. Six could not be reached. Fifteen dyads were interviewed; however, one could not be reached to finalize the story and therefore is not included. Please see Appendix A for a participating Veteran's story, for which permission to publish was obtained.

See Table 1 for participating Veteran and caregiver demographics. Fourteen Veterans participated, all White men between age 70 and 98 (M =77.5). One Veteran was widowed, one divorced, and the rest were married. Caregivers were female family members, mostly spouses, with two adult children, living with Veterans. Based on most recent cognitive evaluation, which was completed with outpatient clinic staff within fifteen months of interviews and gathered via chart review, three Veterans had no cognitive impairment, five had mild, five had moderate, and one had severe



Table 1. Veteran-caregiver Dyad demographics and interview details.

Dyad ID	Veteran Age	Veteran Cognitive Score	Caregiver Relationship	Interview Platform	Interview Duration (Mins)	Story Length (Words)
1	82	Moderate	Spouse	Video	33	575
2	79	Mild	Spouse	Telephone	90	1383
3	70	Mild	Spouse	Video	42	737
4	75	Mild	Spouse	Telephone and Video	52	592
5	82	Moderate	Adult Child	Video	60	1058
6	76	Severe	Spouse	Video	50	633
7	76	Mild	Spouse	Video	30	495
8	79	Moderate	Spouse	Video	65	1056
9	77	Normal	Spouse	Telephone and Video	90	1398
10	98	Moderate	Adult Child	Video	35	550
11	77	Moderate	Spouse	Telephone and Video	76	1328
12	73	Normal <sup>a</sup>	Spouse	Video	30	1098
13	70	Normal	Spouse	Telephone	50	814
14	71	Mild	Spouse	Video	35	1024

Note. Scores represent most recent evaluation of cognitive ability, either the Montreal Cognitive Assessment (MoCA) or the Mini-Mental State Examination (MMSE), completed with clinic staff within the last fifteen months. Scores on the MoCA and MMSE are categorized into no impairment (MoCA≥26; MMSE≥25), mild impairment (MoCA18-25; MMSE 20–24), moderate impairment (MoCA 10–17; MMSE 13–19), or severe impairment (MoCA<10; MMSE ≤12). <sup>a</sup>MMSE score; all others MoCA.

cognitive impairment, according to scoring guidelines for the Mini-Mental State Examination, or MMSE (Folstein, Folstein, & McHugh, 1975), and Montreal Cognitive Assessment, or MoCA https:// www.mocatest.org/faq/ (MoCA:Montreal Cognitive Assessment).

# **Post-interview questionnaires**

Dyads completed two post-interview questionnaires about technology and interview experience at different time points. Questionnaires included statements with five-point Likert scales of agreement ranging from strongly disagree (1) to strongly agree (5) and a Visual Analog Scale (VAS) (Bushnik, 2011) for Veterans with communication impairments. See Appendices B and C for questionnaires. Clinical trainees completed questionnaires virtually with dyads.

**Technology Experience** 

Immediately following interviews, dyads completed a five-item questionnaire about technological experience. Items included ability to see and hear during interviews. This questionnaire was modified from a dementia telehealth study (Moo et al., 2014).

#### Interview experience

Following story readback (which was within a week of interviews), dyads completed a four-item questionnaire about interview experience. Because the questionnaire included items about the overall process, including Veterans' intention to share their story, trainees administered this questionnaire after finalizing Veteran stories. Scores on three items were 5-point Likert scales, with one Yes/No/ Not Sure option.

#### Results

See Table 1 for interview details. According to trainee notes and finalized stories, interview duration ranged from 30 to 90 minutes (M = 60) and stories ranged in length from 495 to 1398 words (M = 910 words). Interviews with Veterans with no-to-mild cognitive impairment ranged from 30 to 90 minutes (M = 52), while interviews with Veterans with moderate-to-severe impairment ranged from 33 to 76 minutes (M = 53). Completed stories with Veterans with no-to-mild cognitive impairment ranged from 495 to 1398 words (M = 943), while stories with Veterans with moderate-to-severe impairment ranged from 550 to 1328 words (M = 867).

Caregivers participated in ten interviews. Caregiver participation varied, but trainees took a Veteran-centric approach by directing questions to Veterans. Veterans responded to clinical trainees most of the time, except for one Veteran with severe cognitive impairment whose caregiver provided most details. Caregiver contribution included prompting to remind Veterans of events, clarifying details, or rephrasing questions into Veterans' more familiar language. Four interviews were conducted with Veterans alone. Of these, one Veteran had no cognitive impairment, two had mild, and one had moderate cognitive impairment.

Regarding technology, according to trainee notes, five Veterans participated using laptops, one used a desktop computer, four used tablets, two used smartphones, and two used phones without videoconferencing. Most (n = 11) interviews were conducted using VHA's videoconferencing software, VVC, one used another videoconferencing platform, and two were phone only. For all interviews involving videoconferencing, caregivers set up technology. For the two interviews by phone only, Veterans initiated and completed interviews without caregiver assistance.

Technical disruptions such as lost audio or video lag occurred in most (n = 10) interviews, averaging less than three minutes and ranging from 0-10 minutes, with trainees providing support. Glitches did not prevent interview completion; however, of those using VVC, three converted entirely to phone due to technical disruptions. One dyad used a phone for audio and VVC for video when audio failed. Interview duration and story length were shorter for interviews conducted over video than for phone or combination: video interview duration, M = 42.2 and story length, M = 803 words, versus phone/combination interview duration, M = 71.6 minutes and story length, M = 1103 words.

Trainee notes and group discussions also identified overall challenges related to remote MLMS challenges with interviews. These included

technological set up and glitches, communication, interviewing individuals with deficits such as memory loss, and considerations for interviewing dyads. See Appendix D for suggested strategies for adapting interviews.

# Technology experience

See Figure 1 for mean Technology Experience ratings across dyads. Most dyads indicated positive experience, with highest ratings for ability to hear clearly (M = 4.9, SD = 0.4, range 4-5) and ease communicating (M = 4.7, SD = 0.6, range, 3-5),followed by comfort with technology (M = 4.6, SD = 0.9, range, 2–5), ability to see (M = 4.6, SD =1.1, range, 1-5), and enough technical assistance (M = 4.5, SD = 0.6, range, 3-5). There were two instances of disagreement or strong disagreement. Dyad 8 disagreed with being comfortable using technology (notes indicated this dyad experienced audio loss necessitating a phone) and dyad 14 strongly disagreed with ability to see, with trainee notes indicating that video frequently froze.

# Interview experience

See Figure 1 for mean Interview Experience ratings across dyads. Most ratings were positive, with the highest response for the process of sharing the story being worthwhile (M = 4.4, SD = 0.8, range, 3–5), followed by belief that telling stories allowed Veterans to look back on their lives (M = 4.3,

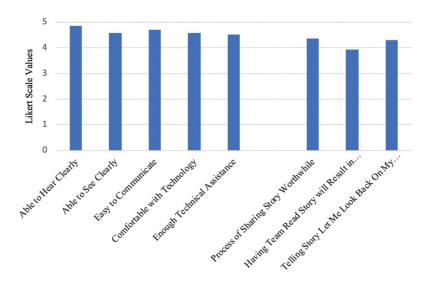


Figure 1. Veteran-caregiver ratings on technology and experience questionnaires.



SD = 0.9, range, 2–5). There were two instances of disagreement, with dyad 13 disagreeing that having the medical care team read the story will help them provide better treatment and that telling the story allowed the Veteran to look back on his life. All but one Veteran indicated planning to share stories with family or friends.

## **Discussion**

This paper presents findings from a program evaluation of My Life, My Story (MLMS) conducted using telehealth technology with Veterans with cognitive concerns and caregivers. All Veterans successfully completed remote interviews, with caregivers assisting with more complex aspects of technology and participating in most interviews. Level of cognitive impairment did not appear to affect interview duration or story length, though interviews conducted over video tended to be shorter than those by phone only or combination. Given the small sample, it is difficult to draw conclusions from these findings.

Regarding Interview Experience, there is limited literature about MLMS program outcomes, with no extant study presenting patient outcomes. Of the one study presenting MLMS clinician outcomes, most clinicians strongly agreed that reading Veterans' stories had an impact and was a good use of clinical time (Roberts et al., 2020). This aligns with our finding that Veterans found the process of sharing their story worthwhile. Further evidence for Veteran and clinician perspectives on MLMS would help to validate program aims of enhancing Veteran-care team communication.

Technology Experience was mostly positive, highlighting the acceptance of technologymediated communication and population-specific considerations. Highest rated items were ability to hear and ease communicating, underscoring the importance of effective communication in videoconferencing (Gately et al., 2020; Serwe, Heindel, Keultjes, Silvers, & Stovich, 2020). Low ratings align with evidence for the negative impact of technological glitches, which may cause patient frustration (Almathami, Win, & Vlahu-Gjorgievska, 2020). Though interviews were completed despite glitches, with strategies such as switching to phone, it is important to note that technical glitches may have negative consequences on provision of health care (Gogia et al., 2016).

Related to technology, dyads used a range of devices, with most Veterans using videoconferencing. However, videoconferencing required caregiver assistance, underscoring considerations for dementia and potential access gaps. Caregiver participation aligns with their role in technology-based dementia interventions (Astell et al., Lindeman, Kim, Gladstone, & Apesoa-Varano, 2020; Sriram, Jenkinson, & Peters, 2019). It also reflects the inherent complexity of telehealth (Pereira, 2020), with videoconferencing potentially requiring enabling a camera, clicking on a link, or downloading software. This may necessitate caregiver assistance (Padala, Wilson, Gauss, Stovall, & Padala, 2020), particularly for dementia. In our work using videoconferencing for a dementia home safety evaluation, which required ambulating the home under remote direction, we employed caregivers due to the complexity of the task (Gately et al., 2020).

Despite their involvement, caregiver needs in video visits are unknown (Bertoncello, Colucci, Baldovin, Buja, & Baldo, 2018). Caregivers may face similar challenges as older patients, including decreased digital skills (Casillas et al., 2020). Individuals with dementia may face barriers if caregivers are not available. Further, while some Veterans participated using phone only, videoconferencing has additive value to quality of life and caregiver burden when compared to phone alone (Lai et al., 2020). Videoconferencing also affords a view of patients in their natural context, providing opportunities for clinical observation (Moo, 2020). Therefore, while phone may be better than nothing, video may enhance the experience for patients and clinicians.

Our findings also suggest considerations for balancing caregiver involvement with MLMS's patientcentric approach. Regarding triadic communication, that is, communication involving patients, family members, and care teams (Laidsaar-Powell et al., 2013), evidence suggests that caregiver presence often leads to increased provider understanding of health status and increased advocacy for individuals with dementia (Gitlin & Hodgson, 2016; Schmidt, Lingler, & Schulz, 2009; Vick et al., 2018). While gathering the most accurate information is crucial, it is important for clinicians to not rely solely on



caregivers but prioritize patient perspectives (Mitnick, Leffler, & Hood, 2010).

# **Limitations and future directions**

This study's small, homogenous sample limits generalizability. We did not systematically capture caregiver's contribution to stories. While recognizing caregivers' vital role in dementia care, Veterans' responses may have differed if caregivers were not present. Future studies may formally assess caregiver contributions to My Life, My Story interviews. Similarly, comparing remote and traditional face-to-face interview experience is another avenue for future studies. Gathering baseline prior use of technology, and more granular details on technical glitches, may help to contextualize Technology Experience ratings and inform the potential need for technical support.

#### **Conclusion**

Technology allowed Veterans with cognitive concerns and their caregivers to participate in My Life, My Story during COVID-19. All Veterans participated and contributed stories despite cognitive concerns ranging from mild to severe, often aided by caregivers. Participation in MLMS enabled inclusion of Veteran stories in the medical record at a time when communication between families and care teams was limited. Many older adults rely on caregivers to advocate and provide information to care teams about what they value most (Schwartz et al., 2020). At times when caregivers are unable to be present with care teams (such as during COVID-19), remote MLMS may increase understanding of patients by care teams.

# **Clinical Implications**

- When conducting narrative life story interviews with individuals with cognitive impairments, simplify language, consider broader questions that do not rely on memory, and encourage sharing of feelings over facts.
- During virtual interviews, caregivers are critical to setting up and trouble-shooting videoconferencing technology.

• Caregiver collaboration during interviews, including prompting, clarifying and providing details, may facilitate patient engagement.

# **Acknowledgments**

The authors wish to acknowledge all the Veterans and caregivers who generously contributed their life stories to this project and Andrew Delao, OT/s, for his contribution as interviewer. We would also like to thank Sarah A. Poole, LICSW at the Neurocognitive Clinic for assistance with recruitment of Veterans and Nadene E. Stillings, LMHC, ATR-BC, Creative Arts Therapist at the VA Bedford HCS for providing education regarding the MLMS process and additional resources.

#### **Disclosure statement**

No potential conflict of interest was reported by the author(s).

# **Funding**

This study was not funded.

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## Disclaimer

This material is the result of work supported with resources and the use of facilities at the Department of Veterans Affairs. The contents do not represent the views of the U.S. Department of Veterans Affairs or the United States Government.

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